


Collaboration and Outside-the-Box Thinking to Overcome Training-Related Challenges for Including Patient Stakeholders as Data Collectors in a Patient-Engaged Research Project

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Abstract

Including patient stakeholders as active members of the research team is essential to a patient-engaged research design. To hire community-based research staff for a study comparing the effectiveness of diabetes self-management programs for Latinos, we had to provide phlebotomy training which was not allowed under the fiscal guidelines of our funders. By collaborating with partners at the Clinical and Translational Science Center, we were not only able to find a creative solution and provide phlebotomy training to our research staff but the process of creating the training also contributed to improved infrastructure for patient-engaged research at our institution.

Keywords

patient-engaged research, training, Latinos, phlebotomy

Introduction

Patient-engaged research design is increasingly recognized as an important mechanism for ensuring that patients' interests, concerns, and perspectives are included in the focus and design of health research studies. Patients, communities, health-care providers, and researchers are working collaboratively to develop engaged research approaches, and funders are including engagement as an accepted research paradigm or even as a priority. Involving patients, caregivers, individuals such as community health workers, or other patient stakeholders who are culturally matched with participants in a research study as project staff or identifying patient stakeholders who can help build relationships and conduct outreach in the community can improve the scientific quality of a research project and encourage recruitment (1-6). Patient stakeholders often contribute knowledge and skills that may be lacking when research is designed and implemented by university-based professionals without patient stakeholder input (1,3,4). Having patient stakeholders involved in recruitment or gathering data can facilitate the creation of a nonthreatening

environment and help build rapport with participants. This approach can build trust by demonstrating respect for participants' cultural values, contextual realities, and language needs (4,6-8).

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The trust component of the relationship between researchers and the community is particularly key (1,4). Commonly reported perspectives among patients and Community members are that researchers only come around when they want to get people to participate in their study, that they merely appropriate information from people, or that they convene “advisory boards” for projects where members do not really do anything meaningful.

Patient-engaged project design can change this dynamic by placing patients and community members in relation to the research in more than a traditional advisory role. However, challenges to including patient stakeholders as active, integrated members of a research team remain. Creating capacity for engaged research requires the development of collaborative work relationships and new ways of thinking about the role of university resources and infrastructure (8-10).

Description

Background

Here, we discuss our experience working with patient stakeholders to develop and implement a comparative effectiveness study of 2 models for diabetes self-management used by programs in Albuquerque, New Mexico, that serve a large number of Latino patients from low-income households (11). Our project team includes patient stakeholders working in multiple capacities—co-principal investigator (Co-PI), project coordinator, community site director, and 3 data collectors. We began collecting data in February 2017, and over the 3-year life of the project, we will enroll 480 participants. Data collection is planned to occur at 4 time points—baseline, 3, 6, and 12 months. Biological samples, including blood for hemoglobin A_{1c} (HbA_{1c}) testing, will be obtained from half of the participants at all 4 data collection appointments.

The Challenge

Hiring data collectors from the patient community of study was a key component of our patient-engaged research design. Not only would this ensure a patient-centered perspective in our approach, but we believed that having patient stakeholders as data collectors would make our research more culturally competent and would therefore facilitate recruitment and retention of participants from a population that is generally considered difficult to include in research studies (1-4).

The design of our research requires that we have data collectors who can administer a survey and at the same time, collect blood for HbA_{1c} testing. However, we knew that we could not expect patient stakeholders to have research experience or to have training in phlebotomy. This meant that we would need to provide our data collectors with a variety of project-specific trainings, including the use of password-protected iPads and the secure database portal, instruction in survey administration and electronic database entry using the iPad, and training in phlebotomy. Elsewhere, we discuss our approach to creating a database for use by patient

stakeholder data collectors and training them to conduct research, and how this built capacity in the community. But the need for competent and certified phlebotomy skills among our data collectors presented an unexpected challenge to us as we prepared to launch the study.

We had identified a private sector phlebotomy-training course where the data collectors would be able to learn the skills they needed in a 2-day session and we included this in our budget. However, the funder indicated that phlebotomy training was not allowable under their fiscal guidelines. Without funding, this private sector training was not an option for us, and it seemed as if it would not be possible to train our data collectors in the context of our project. The fact that our data collectors were hired by our primary patient partner organization under a subaward contract from the University of New Mexico (UNM) meant that they were not UNM employees—and therefore, it was not possible for us to access some UNM-based training options. Because data collectors were lay members of the community without a medical background, we were told that it would be difficult to train these individuals. Moreover, because a number of members of our team are monolingual Spanish speakers, we needed to either have the training conducted in Spanish or allow members of our team to do a simultaneous interpretation during the instruction. We could not find any program that had the training available in Spanish, and none would consider doing it with interpretation, as this was seen as too complicated.

Therefore, just as the project was getting off the ground, we found ourselves in a huge bind. We had to hire patient stakeholder data collectors and they had to be trained in phlebotomy, but the existing infrastructure and practice did not provide us with options. We were challenged to figure out a way for them to receive the training.

Results

Solution to the Challenge

The UNM Clinical and Translational Science Center (CTSC) provides multidimensional assets and resources for research, including a sophisticated clinical research unit, investigator training programs, biomedical informatics tools, a large-scale drug discovery program, a clinical research data warehouse, and commercialization facilitation. The CTSC is sponsored by the National Center for the Advancement of Translational Science (NCATS) which recognizes the importance of community-engaged research. Specifically, NCATS aims to “ensure community engagement in the research process,” and as such, they recognize that “research institutions must collaborate with community organizations to identify and understand public health needs,” and that, among other objectives, “Clinical and Translational Science Award (CTSA) Program hubs (must) collaborate with public health professionals, health-care providers, researchers, and community-based groups to develop methods of effective community dialogue and research” (<https://ncats.nih.gov/ctsa/community>).



Figure 1. Data Collector Phlebotomy Training Graduation/Certificates.

The CTSC Translational and Clinical Laboratory (TCL) would be providing HbA_{1c} testing for our project, and given the dictates of the NCATS, we reapproached CTSC about the possibility of providing phlebotomy training to our study team. Despite their initial negative response, we got the TCL to reconsider by asking if there were specific reasons that made it impossible for them to do the training we were requesting other than that such a training had not previously been done. In thinking about this question, it became clear that there really were no insurmountable barriers, and after reviewing state certification requirements, TCL staff actually became enthusiastic about the prospect of providing phlebotomy training for lay staff. They put together a customized training program to be delivered in a series of short, small group sessions.

Phlebotomy Training

Between November 2016 and January 2017, in collaboration with the CTSC, we conducted a 7-session phlebotomy-training course. Seven members of our research team participated—3 data collectors, the Co-PI, the research coordinator, the research manager, and the community site director. The training consisted of an initial orientation session with educational content and practice using “fake arms” designed for phlebotomy instruction, plus 6 practical sessions. Members of our team provided interpretation for non-bilingual data collectors and for all TCL instructors (as none of them spoke Spanish), and TCL instructors accommodated the time necessitated by this process. In the orientation session, the instructor covered basic vein anatomy, safety procedures, use of instruments and materials, and venipuncture protocol. In the subsequent practical sessions, the trainees practiced drawing blood from each other or from volunteers. In order to receive a certificate of completion from the TCL (Figure 1), the trainees had to achieve 10 clean blood draws—8 from the arm and 2 from the hand. All trainees completed training and received certificates in January 2017.

Lessons Learned

The collaboration between our research team and the CTSC was key to obtaining the training for patient-engaged research in the format that we required without excessive cost. Although language was one of the biggest barriers to finding a training option for our data collectors, the TCL staff discovered that they were able to provide high-level training content even with using interpretation. Although the interpretation did slow the training down a bit, the process was not detrimental to the training experience. Because the training was being done for individuals who did not come from a medical background, it did require the trainers to avoid medical jargon and develop appropriate training materials. However, in the process of developing our training, TCL staff realized how valuable this sort of training could be if they could offer it to other investigators and teams interested in community-engaged research or to community partner organizations. This aligns well with mission of UNM to serve the needs of the community.

Conclusions

At first glance, it seemed as if it was not going to be possible to create a phlebotomy training for our patient stakeholder data collectors. Such a training had never been done before. But by thinking outside the box, we were able to find a creative, collaborative solution to the challenge we faced. The UNM has many studies that work with members of the community, but the CTSC had never considered this type of training as a possibility before. With our phlebotomy training, we created a precedent within the university, and because of the success of the training, the plan now is that the CTSC will create a routine mechanism for training lay staff in community-engaged research endeavors. However, the impact of this experience has been even broader. In addition to phlebotomy, plans are in the works for future CTSC training opportunities for community- and patient-engaged research that may include Human Subjects-compliant recruitment procedures, consenting and data collection protocols, medical translation, instrument development, and survey administration. In figuring out how to train Spanish-speaking patient stakeholder data collectors, we created capacity for our project, for our patient partner organization, and for our individual patient stakeholder data collectors. But additionally, the solution we found for overcoming the particular challenge we faced related to phlebotomy training has had a broader impact, positively influencing the UNM infrastructural environment to further support engaged research design.

Authors' Note

The views presented in this work are solely the responsibility of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee. This article is a case report that discusses experiences of the research team in developing a patient-engaged research project. No research was conducted to support the production of this manuscript. The discussion here does

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Declaration of Conflicting Interests

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